

SOME QUESTIONS ABOUT ME/CFS TO WHICH CREDIBLE ANSWERS ARE URGENTLY REQUIRED

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(prepared for The Countess of Mar's various meetings with MRC, MPs and Ministers in March /April 2004 by Professor M Hooper in collaboration with the ME/CFS community)

Summary of Key Issues:

- For far too long, Government Ministers and the MRC have refused to listen to anyone other than Wessely School psychiatrists and consequently have allowed the situation regarding ME/CFS to become chaotic and to spiral out of control
- Facts have been consistently distorted
- Patients' needs are still not being met
- Current PACE proposals reflect the desires of Wessely School psychiatrists who have staked their careers on "eradicating" ME and proving that "CFS" is a mental disorder, not on management strategies that have been shown to be of most benefit to sufferers (ie. complementary approaches)
- The financial interests of the insurance industry have been allowed to take precedence over the needs and care of ME/CFS patients
- There has been a relentless determination by those with vested interests to re-classify ME/CFS as a mental disorder
- Vested and competing interests have not been declared
- To grant more money in such large sums for more trials of management approaches that have already been clearly shown not to work appears to be both irrational and scandalous

The CMO's Working Group on "CFS/ME"

- Why were the competing interests of the most influential members of the CMO's supposedly "independent" Working Group on "CFS/ME" never declared? For example:
 - (i) Dr Charles Shepherd and Professor Simon Wessely's membership of HealthWatch, with all the attendant HealthWatch anti-ME / anti-alternative + complementary medicine baggage --- since the late 1980s HealthWatch has carried out a sustained and vicious attack on ME patients, most publicly and notably by its activists Caroline Richmond (a journalist) and, even more vitriolically, by Dr Michael Fitzpartick, its medical writer who also writes for "spiked" (an on-line publication), who is known for his publications in which he attacked the CMO for taking ME seriously, claiming that the CMO's stance is "a

surrender of medical authority to irrationality". Charles Shepherd is a self-proclaimed "active" member of HealthWatch and has published many articles against alternative and complementary medicine. This is relevant because the CMO's report was supposedly looking at *all* management approaches, including alternative and complementary approaches, which are the very approaches that HealthWatch was set up to oppose: it now denies this, but its early documents are unequivocal.

- (ii) Deputy Chair of the CMO's Working Group Professor Tony Pinching's membership of the RCP committee that produced a fiercely anti-allergy / anti-alternative + complementary medicine report (that report had to be withdrawn because Fellows of the College exposed it as being wildly inaccurate), and his disparaging views on "CFS" as expressed in Prescribers' Journal 2000:40:2:99-106 (published during his tenure as Deputy Chair of the CMO's Working Group), including his view that "CFS" patients "*seek abnormal test results to validate their illness*" and that "*the essence of treatment is activity management and graded exercise*". Such views are not supported by the evidence.
- (iii) Wessely's personal involvement with PRISMA, a healthcare company working with insurance companies to arrange "rehabilitation programmes" of cognitive behavioural therapy and graded exercise for those with "CFS/ME" and which is now providing such regimes for the NHS (Wessely is listed a Corporate Officer and as a member of the Supervisory Board and is higher than the Board of Management). This is the same package which, via the York Centre for Reviews and Dissemination (CRD) Systematic Review underpins the recommendations of the CMO's "independent" Report. Wessely was an adviser to the team which carried out that systematic review of the literature, so once again, undeclared vested interests are rampant.
- (iv) The Linbury Trust (ie. Lord (David) Sainsbury of Turville's family trust) partly funded the CMO's Working Group and is well-known for its stance on "CFS": since 1991 Linbury has been the major source of funding for Wessely et al's "chronic fatigue" studies which they inaccurately equate with ME/CFS. Linbury's relationship to the Government Science Minister Lord David Sainsbury (who has given £11 million to the Labour Party and who controls all the Research Councils, including the MRC and whose personal biotech companies have received much attention lately over the issue of GM technology) is an undeniable competing interest. Linbury's published view is that its management approaches for "CFS" deal only with graded exercise, CBT and anti-depressants. How could the CMO's Working Group Report not reflect this particular vested interest?

- (v) The use by the Centre for Reviews and Dissemination (which carried out the so-called “independent” York Review of the literature) of Wessely’s own database as a basis for their study of the literature. Professor Iain Chalmers, Director of the Cochrane Collaboration, whose “unbiased” databases were also used for the “systematic review” of the literature for the CMO’s Working Group is, with Wessely and Shepherd, a member of HealthWatch. Inevitably, the CRD / York Systematic Review found that CBT and graded exercise were the best management approaches, but where is the *proof* that ME/CFS (as distinct from “chronic fatigue”) is amenable to CBT? It is certainly not in the York Systematic Review, so *why* is CBT still being pushed as the management of choice by both the MRC and by NICE, and why has Government granted £8.5 million for yet more studies by these same psychiatrists on something that has already been shown to be harmful to those with ME/CFS?
- (vi) The long-time and well-documented involvement of Wessely School psychiatrists with the disability insurance industry in respect of ME/CFS claims (especially Wessely himself, Peter White and Anthony Cleare --- for detailed information, see “Further reading”). The media has now picked up the key issue, namely that *“its all about selling the idea of a disorder – the idea of mental illness –in order to get more funding. The whole business of creating psychiatric categories of ‘disease’, formalising them with consensus, and subsequently ascribing codes to them, which in turn leads to their use for insurance billing, is nothing but an extended racket. The perpetrators are, of course, feeding at the public trough”* (Westminster Independent, 1st March 2004, The Citizens Commission on Human Rights)
- Why was the extensive published literature (from more than 60 mainstream international journals) that was provided for the Working Group so totally and resolutely ignored (ie. the literature that shows many biomarkers of an organic pathoetiology and the absolute and urgent need for subgroups of “CFS” to be studied)? Why was the agenda pre-set by the influential psychiatrists who dominated that Working Group?
 - Why does the UK Government listen only to Simon Wessely as their official “expert” on ME/CFS when his beliefs have been so repeatedly questioned in the international literature and when he has been publicly shown to dismiss ME as a “non-disease” (as in the BMJ, February - April 2002, when he orchestrated a vote of doctors on what they considered “non-diseases” that are best left medically untreated (in which he is believed to have proposed ME). The results were widely reported in the media, for example: *“Obesity and ME are non-diseases, say doctors”*. Even though ME/CFS has been formally classified as a neurological disorder by the WHO in the ICD since 1969, Wessely believes ME does not exist except in the minds of sufferers and that

“CFS” is a somatisation disorder. Such a belief flies in the face of the international evidence, but Wessely refuses to accept the neuro-immunological, cardiovascular, respiratory and musculoskeletal evidence (recent convincing research confirms that ME/CFS is a complex vasculitis: the occurrence of vascular manifestations has been in the ME literature since 1938 but along with all the other evidence that does not accord with Wessely’s intention to re-code ME/CFS as a psychiatric disorder, it is all just ignored or denied by this group of psychiatrists).

- Why, in contempt of the evidence, did the CMO’s report advise that only *basic tests* are necessary and appropriate for those thought to have ME/CFS, when the whole world knows that such tests will be normal in 90% of those with ME/CFS, and why did the Report specifically advise that no immunological or nuclear medicine investigations should be done, when those are the very investigations which are delivering hard evidence of an organic pathoetiology in the USA, Belgium and other countries?
- Why did the authors of the CMO’s Working Group Report deliberately mislead the medical community by providing misinformation about the classification of ME/CFS in the ICD, even though this misinformation was pointed out to the Key Group members long before publication?
- Why were the authors of the CMO’s Report permitted deliberately to obfuscate the established terminology and classification of ME/CFS by creating the new term “CFS/ME”? After the Report was published, Wessely himself offered the explanation in the following terms, referring to “constructive labelling”, claiming that such labelling means “*treating chronic fatigue syndrome as a legitimate illness while gradually expanding understanding of the condition to incorporate the psychological and social dimensions*”. It must be pointed out once again that Wessely et al **are not, by their own definition, looking at those with ME/CFS but at those with idiopathic chronic fatigue**. Since this impacts on management approaches and service provision, what steps is Government taking to make sure this important distinction is brought to the attention of all healthcare professionals in the UK?

The MRC

- The panel chosen by the MRC to provide a strategy for the direction of future research into “CFS/ME” included two people who, far from being “independent” and “fresh minds” as announced by Dr Diana Dunstan of the MRC, are known to favour

the psychiatric model of ME/CFS and for promoting cognitive behavioural therapy and for their strong connection to the Linbury Trust, which funds so much of the psychiatric “research”. Those two people (Prof Alan McGregor of Kings and Prof Philip Cowen of Oxford) have actually co-authored papers with Simon Wessely (McGrgeor) and Mike Sharpe (Cowen) and Cowen is mentioned in Wessely’s book on CFS. Sharpe is known to have recommended to medical insurance companies that claimants with ME/CFS should be subjects of covert video surveillance (and let us not forget that in its “Chronic Fatigue Syndrome Management Plan” the insurance company UNUM proclaims: “*DIAGNOSIS: Neurosis with a new banner*”. It was simply untrue that these people were “fresh minds” to the matter and the ME community was well aware of this. In his letter of 15th July 2002 to Simon Lawrence of the 25% ME Group, Radda himself (former CEO of MRC) ducks out of the issue by saying “you cite papers from some years ago” (he could not deny those papers) but then stated that the inclusion of McGregor and Cowen on the panel “is consistent with MRC’s intention to select the working group from experts in various fields who do not specialise in CFS/ME”. How could he say this with any credibility, when McGregor is listed in the Linbury publications as being a “**Member of the Linbury Advisory Panel on CFS**” and is so closely involved with the psychiatric model? The MRC has totally lost face over this, as well as the confidence and trust of the international ME/CFS community, including clinicians, researchers and patients themselves.

- Why is no research into the organic pathology being funded by the MRC --- the MRC always says that the research proposals it receives for ME are not of enough merit to warrant funding but this is disputed --- one of the reasons given was that the topic was not of sufficient public interest. Is the real reason because of powerful vested interests (eg. Minister for Science Lord Sainsbury of Turville)? What was Wessely’s influence when he was on no less than 3 MRC Boards (the Health Services and Public Health Research Board, the Neurosciences and Mental Health Group and the Monitoring and Evaluation Group)?
- The CEO of the MRC (now Prof. Colin Blakemore) is supposed to oversee RESEARCH, so it needs to be pointed out to him just how much credible research on ME/ICD-CFS there is (eg. all the international conference reports and publications), but in the UK this research is consistently ignored, trivialised or dismissed by Wessely et al and UK clinicians have been deprived of this information in their own UK journals (which have been full of Wessely’s beliefs, seemingly as editorial policy)
- How can the MRC possibly justify the granting of millions of pounds sterling to Wessely School psychiatrists given that their work has been universally shown to be so flawed? Even these psychiatrists themselves concede that for those with ME/CFS who have taken part in their studies of CBT and graded exercise, there is no lasting benefit at follow-up.

- How can the MRC be unconcerned that the PACE trial inclusion criteria are the discredited Oxford 1991 criteria? The Oxford criteria have been shown to have no predictive validity and there has never been international consensus about them: the Oxford criteria are used only in Britain and have never been adopted internationally . It is virtually unheard of for studies to use criteria that have been superceded, as is the case with the 1991 Oxford criteria. The Oxford criteria identify what the later (1994) CDC international criteria call “idiopathic chronic fatigue” as opposed to people with ME/CFS: the stricter criteria select those with neurological symptoms (which would not be responsive to CBT) and, crucially, the Oxford criteria specifically exclude people with ME/CFS or any other neurological disorder and state that the suggested control group should be those with neuromuscular disorders. The PACE grant proposal entitled “RCT of CBT, Graded Exercise, and Pacing versus usual medical care for the chronic fatigue syndrome” actually states: “**We chose these broad criteria in order to enhance recruitment**”. How can this be “evidence-based medicine”? Is the MRC entirely content that the same proposal also states “**Those subjects who also meet the criteria for “fibromyalgia” will be included**”, given that fibromyalgia is classified in the ICD at M79 as a distinct entity (whereas ME/CFS is classified at G93.3) and that FM is a quite separate disorder from ME/CFS, with a discrete biomedical profile that is entirely distinct from that found in ME/CFS --- for example, there is no orthostatic intolerance in FM but there is in ME/CFS; in FM there is raised ET-1 (endothelin -1) but not in ME/CFS; in ME/CFS there is acetylcholine sensitivity in the endothelium but not in FM, and Substance P is raised in FM but not in ME/CFS. Importantly, on 3rd June 1998, Baroness Hollis from the then Department of Social Security sent a letter to Lindsay Hoyle MP (reference POS(4) 3817/88) which says “The Government recognises that fibromyalgia syndrome (FMS) is a condition which can cause a wide variety of disabilities from mild to severe. In some cases it can be a very debilitating and distressing condition. People with FMS who need help with personal care, or with getting around because they have difficulty in walking, can claim Disability Living Allowance to help with meeting related expenditure”. From this letter, it is clear that Government already recognises fibromyalgia as a distinct entity. Further, in the CMO’s UPDATE of August 2003 (a paper communication from the CMO sent to all doctors in England) entitled “Improving Services for Patients” there is an item called “Fibromyalgia – A Medical Entity”. This means that the CMO considers fibromyalgia to be a separate, stand-alone medical entity (and the fact that it is designated a “medical” disorder means that it is not considered to be “psychiatric” disorder). How can the deliberate inclusion of patients with fibromyalgia not result in skewed and meaningless conclusions when the patients being entered in the PACE trials are, from the outset, not clearly defined? The Director of the PACE database design and management is named as Professor Simon Wessely, so is it co-incidence that the HealthWatch dogma shines through again even in this proposal, which states “**Subjects will be discouraged from starting alternative treatments**”. Of great significance is the fact that those who are too sick to attend hospital will be completely excluded from the PACE trials, so how representative of efficacy will the results be? The PACE trial proposers themselves say that PACE is not expected to help more than 30% of patients (and the severely affected are to be excluded, so this means 30% of those who are not severely affected). As CEO of the MRC, does Colin Blakemore feel confident that the PACE trials are an appropriate use of public funding?

The National Institute for Clinical Excellence (NICE)

- The CMO and the MRC have asked NICE to develop clinical guidelines for the diagnosis and management of “CFS/ME”. Given that NICE funds the “Effective Health Care” bulletins (published since 1999 by the RSM) which are disseminated throughout the NHS (including the issue on CBT and graded exercise as management of choice for ME/CFS), how can NICE now be unbiased in its advice when its views on this are already established and can be seen to be biased in favour of the psychiatric model? (see “Interventions for the management of CFS/ME” Effective Health Care 2002: number 7: volume 4:). This was published on 23rd May 2002 and was disseminated throughout the NHS, having been the subject of a press release and of a mail-shot promotion by the Royal Society of Medicine to all members of its Section of Neurology and Psychiatry which stated **“You will, I am sure, find this particular copy of *Effective Health Care* very useful, so once you have finished with this copy, please distribute it to any colleagues whom you think might also find it of use”**.
- In the light of the above, will the intended NICE guidelines on the management of ME/CFS include the recommendations of the Canadian Case Definition for ME/CFS (Carruthers BM et al: JCFS 2003;11 (1):7-115? If not, can the reasons why this is to be resisted in the UK be explained. If there is to be any such resistance in the UK, is it related to the expressed views of Professor Simon Wessely on the Canadian Case Definition (who is known to be against the Canadian Case Definition on the grounds that the authors are not unbiased scientists, even though the authors include such world experts as Professor Kenny de Meirleir from Belgium and Dr Daniel Peterson and Professor Nancy Klimas from the US).

The UK WHO Collaborating Centre “Guide to Mental Health in Primary Care”

- What active steps is Government taking to correct the wrong ascription of ME/CFS as a mental disorder in the first edition to this UK Guide, of which more than 30,000 copies have been distributed?
- The recently released second edition of the Guide is re-titled “Guide to Mental and Neurological Health in Primary Care”: what other ICD-classified neurological diseases are included in this Guide apart from ME/CFS?

- What active steps is Government taking to correct the misinformation about ME/CFS that, as a direct consequence of the erroneous information contained in this Guide, is still being promoted by the NHS Information Authority (NHSIA) on its website (ie. that ME/CFS is a mental disorder)?
- In his official letter of 11th February 2004 (to the Countess of Mar) the Health Minister Lord Warner confirmed that the UK Department of Health now accepts the WHO ICD classification of ME/CFS as a neurological disorder and that ME/CFS does not have dual classification as both a neurological and a psychiatric disorder; specifically he confirmed that the Department of Health accepts that Chronic Fatigue Syndrome equates with ME. This does not accord with the recently released second edition of the WHO “Guide to Mental Health in Primary Care” produced by the UK WHO Collaborating Centre based at the Institute of Psychiatry (now re-titled “Guide to Mental and Neurological Health in Primary Care”, toward the cost of which the Department of Health has contributed £60,000) which states: “The terms ‘Post-viral fatigue syndrome’ and ‘(benign) myalgic encephalomyelitis’ (classified under G93.3 ‘neurological disorders’) have been used where there is excessive fatigue following a specific trigger such as a viral disease. **‘Fatigue syndrome’, both chronic and not, has been classified under ‘neurasthenia’, F48.0**”. What active steps is Government taking to correct this anomaly?
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- In the light of the letter from the Health Minister referred to above, what active steps is Government taking to correct the anomaly in the Guide whereby an ICD code of G93.3 is assigned by the UK Collaborating Centre to **“CFS and Somatoform”** disorders in children and adolescents, and why has the term CFS/ME not been used with regard to children here?
http://www.whoguidemhpcuk.org/page_view.asp?c=16&did=2279&fc=021
- Why in the Guide is Chronic Fatigue Syndrome (by which ME is also known, as confirmed by the Health Minister) incorrectly described synonymously with “chronic fatigue”? http://www.whoguidemhpcuk.org/content_show.asp?c=16&fid=1252&fc=011065
http://www.whoguidemhpcuk.org/content_show.asp?c=16&fid=895&fc=005027
- In the second edition of the UK “Guide”, there is still more misinformation: the “Guide” states that there is up to 96% overlap between ME and neurasthenia. This assertion is supported by a single reference that is now almost a decade old and is taken from a paper entitled “Neurasthenia Revisited: ICD-10 and DSM-III-R Psychiatric Syndromes in Chronic Fatigue Patients and Comparison Subjects” (Farmer A et al; British Journal of Psychiatry 1995;167:503-506). Not only does the title refer to “chronic fatigue” patients (who differ from those with ME/CFS) whilst the text refers to patients with “chronic fatigue syndrome”, but the paper explicitly state: “97% (*sic*) CFS subjects fulfilled criteria for neurasthenia (F48) **if exclusion**

criteria were ignored. When the exclusion criteria were applied 40% of CFS subjects fulfilled criteria for CFS". If exclusion criteria are ignored, the research and conclusions are meaningless. The unequivocal statement in the "Guide" that there is up to 96% overlap of symptoms between " 'fatigue syndrome', both chronic and not" and neurasthenia is patently untrue. What is the justification for such a misleading entry in a new edition of the "Guide" funded by the UK Department of Health, and what active steps is Government taking to correct this blatant misinformation?

- What active steps is Government taking to correct the misinformation about ME/CFS being taught to medical students via such standard medical textbooks as Davidson's Principles and Practice of Medicine (eg. the 18th edition / 1999) which has re-classified CFS/ME as a mental disorder, having placed it in the section entitled "*Principles of Medical Psychiatry*"? (ISBN 0443 059 446, *see* p 1092).

Suggested Further Reading

- (all available from the Countess of Mar, House of Lords, London SW1A 0PW)

The following documents are all fully referenced and set out in detail what has been happening to the UK ME/CFS community since Simon Wessely came to prominence in 1987.

The Mental Health Movement: Persecution of Patients? A Consideration of the Role of Professor Simon Wessely and Other Members of the "Wessely School" in the Perception of Myalgic Encephalomyelitis (ME) in the UK. Professor Malcolm Hooper et al December 2003

Notes on the involvement of Wessely et al with the Insurance Industry and how they deal with ME/CFS claims. June 2003

- What is ME? What is CFS? Information for Clinicians and Lawyers EP Marshall, M Williams, M Hooper December 2001

- Consideration of Some Issues Relating to the Published Views of Psychiatrists of the "Wessely School" in relation to their belief about the nature, cause and treatment of Myalgic Encephalomyelitis March 2000

- Denigration by Design? A Review, with References, of the Role of Dr Simon Wessely in the Perception of Myalgic Encephalomyelitis Volume I (1987-1996) and Volume II (1996-1999) pp488

